



## OPERATIONS RESEARCH RESULTS

# The Impact of a Programme to Prevent Mother-to-Child Transmission of HIV: Disease Transmission and Health-Seeking Behaviour among HIV-Positive Mother-Child Pairs in Jamaica

Kevin Harvey and Ingrid Thame

November 2004



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## EXECUTIVE SUMMARY

Estimates indicate that Jamaica is home to 24,000 HIV-positive individuals, including many who are unaware of their status and may be spreading the disease unknowingly. Of that number, 3,500 are women, of whom approximately 900 give birth to 150 to 300 (or perhaps more) HIV-positive children annually. Mother-to-child transmission (MTCT) accounts for 7% of all reported HIV/AIDS cases in Jamaica. In 2002, 81 children under the age of ten were newly reported with AIDS, compared to 66 the previous year, a 23% increase. In the last three years, an average of three Jamaican children died of AIDS each month.

The Government of Jamaica has launched a number of noteworthy programmes to reduce the spread of HIV and mitigate its impact, including one to prevent MTCT. Piloted in 15 clinics in four parishes, the programme was intended to offer (1) HIV testing; (2) antiretrovirals (ARVs) for HIV-positive women in labour and their newborns; and (3) for those same women, counselling that recommended against breast-feeding. Over 8,000 women had accepted these services as of the end of 2002.

Reported here, a 2002–2003 rapid assessment of the programme showed that of the study sample, nearly half of HIV-positive pregnant women did not receive ARVs during labour, and only seven of ten infants did. One reason women did not receive ARVs was their unwillingness to disclose their HIV status at the time of delivery. Stigma and concerns about discrimination are major factors causing such unwillingness. Additionally, procedures for postpartum care and support for HIV-positive mothers and follow-up care were not followed, and counselling before hospital discharge was not performed according to guidelines. Overall, referral mechanisms across the continuum of care were not well defined. Also, roles and responsibilities of staff in preventing transmission were not clear. Lastly, the current system does not give high priority to maternal-child health activities. On the plus side, most women did receive replacement feeding and decided not to breast-feed. Of the mothers who reported having taken ARVs, 10% of their infants tested positive, compared to 24% of infants whose mothers received no medication. However, this was not statistically significant ( $p < 0.2$ ). Nevertheless, the attributable risk of HIV transmission was  $-19$  for those infants whose mothers received the medication, indicating the protective value of nevirapine.

Although nevirapine proved effective, the rate of mixed feeding among those who received it (and hence the rate of MTCT) is still unacceptably high. Stigma and discrimination remain a serious barrier for people living with HIV/AIDS accessing services within the healthcare sector. The possibility of victimization by healthcare workers may contribute to women's failure to disclose their HIV status to hospital providers at the time of delivery.

# **The Impact of a Programme to Prevent Mother-to-Child Transmission of HIV: Disease Transmission and Health-Seeking Behaviour among HIV-Positive Mother-Child Pairs in Jamaica**

## **I. INTRODUCTION**

Jamaica is experiencing alarmingly high rates of perinatal AIDS, now the second leading cause of death among Jamaican children between one and four years. The United States Agency for International Development (USAID) and the Jamaican Ministry of Health asked the Quality Assurance Project (QAP) to evaluate a pilot programme that provides services for the prevention of mother-to-child transmission of HIV (PMTCT). The evaluation results will help refine the PMTCT programme and related care and support systems. The evaluation's specific objectives were to determine (a) sero-conversion rates among infants of HIV-positive mothers who did or did not receive antiretrovirals (ARVs), (b) sero-conversion rates among infants who were or were not breast-fed, and (c) mothers' attitudes toward PMTCT and the presence of stigma and discrimination against these women. The evaluation covered all of 2001–2002 and took place from September 2002 to May 2003.

## **II. BACKGROUND**

### **A. Infection Rates**

Since the onset of the AIDS epidemic over 20 years ago, HIV has infected more than 47 million people worldwide. With more than 2.2 million deaths in 1998, AIDS is the fourth leading cause of mortality, and its impact is continuously increasing. Over 95% of all HIV/AIDS cases and 95% of AIDS deaths occur in the developing world, especially in sub-Saharan Africa and the Caribbean. Most victims are young adults, with women the fastest-growing population at risk of infection.

In the Caribbean region, official figures indicate that 350,000–590,000 people have HIV/AIDS. The percentage of adults 15–49 with HIV/AIDS is estimated at 1.9–3.1%.

Jamaica is experiencing a significant increase in HIV prevalence: It now has the highest rate of increase of HIV/AIDS in the region, accounting for two out of every 60 new cases. In 2002 Jamaica, with a population near 2.5 million (1996 estimate), had 989 newly reported cases: 409 females (41%) and 580 males (59%). The high prevalence of female HIV/AIDS cases, combined with the pre-eminence of heterosexual contact as the mode of transmission, gives Jamaica an alarming proportion of paediatric/perinatal cases: about 7% of the total AIDS cases, while the non-Caribbean countries of Latin America have a 3% rate. HIV/AIDS is also the leading cause of death in Jamaica for men and women in the 30–34 age group. Adolescent females in the 10–14 and 15–19 age groups had a two and three times higher risk of HIV infection, respectively, than boys of the same age: Girls are having sexual relations with older men, who are more likely to be infected than males aged 10–19. The prevalence of HIV/AIDS among pregnant women in Jamaica is approximately 1.6–2%, with St. James Parish at 3.3%.

While reports indicate that of Jamaica's 3,500 women with HIV/AIDS, approximately 900 give birth to 150 to 300 HIV-positive children annually, the number of

### **Abbreviations**

AIDS	Acquired immune deficiency syndrome
ANC	Antenatal clinic
ARV	Antiretroviral
AZT	Zidovudine
CRH	Cornwall Regional Hospital
ELISA	Enzyme Linked Immuno Sorbent Assay
HIV	Human immuno-deficiency virus
KSA	Kingston and St. Andrew
MOH	Ministry of Health
MTCT	Mother-to-child transmission
PMTCT	Prevention of mother-to-child transmission of HIV
QAP	Quality Assurance Project
USAID	United States Agency for International Development
VCT	Voluntary counselling and testing
VJH	Victoria Jubilee Hospital

paediatric AIDS cases may be higher because of poor sero-prevalence data for children. Furthermore, as more women of childbearing age become infected, the number of reported paediatric AIDS cases will likely increase. In 2002, 81 paediatric cases were reported, compared to 66 in 2001, a 23% increase.

These statistics indicate that Jamaica's HIV/AIDS death rate could match those of the worst-affected countries if a significant treatment and prevention programme is not instituted.

### **B. Treatment and Prevention**

Mother-to-child transmission of HIV (MTCT) can occur during pregnancy, labour/delivery, and breast-feeding. The rates of transmission are 15% and 45%, respectively, in developed and developing countries. With proper and timely interventions to prevent transmission, including avoidance of breast-feeding when affordable and acceptable alternatives exist, its rate can be reduced by well over 70%.

Early diagnosis of infected newborns and introduction of prophylaxis against opportunistic infections can significantly increase the length and quality of life of HIV-positive infants. With these therapeutic options and the significant morbidity/mortality rates of HIV/AIDS, a comprehensive MTCT prevention programme is essential.

### **C. Response of the Government of Jamaica**

To fight the AIDS epidemic, the Government of Jamaica is working closely with multilateral agencies: USAID, UNAIDS, the Pan American Health Organisation, the International Development Bank, the World Bank, and others. The government has successfully launched a number of innovative programmes to reduce the spread of HIV and mitigate its impact on communities, including a programme to promote condom use that helped increase the rate of such use from 20% in the early 1980s to 77% in 2000.

The Ministry of Health (MOH) piloted the Mother to Child Transmission Prevention Programme in 1999 in four parishes (Kingston-St. Andrew [KSA], St. James, St. Catherine, and St. Mary). The programme has expanded and by December 2002 was island-wide with all components, including voluntary counselling and testing for HIV (VCT) being available in over 90% of antenatal clinics (ANCs). The Determine<sup>®</sup> HIV rapid test is being used in 15 sites in all four regions (Table 1).

**Table 1. HIV Rapid Testing Sites by Region (Total: 15)**

<b>Regions</b>	<b>North-East</b>	<b>South-East</b>	<b>Western</b>	<b>Southern</b>
Testing sites	St. Ann's Bay Health Centre Annotto Bay Hospital Portland Health Department St. Ann's Bay Hospital	Comprehensive Health Centre Spanish Town Hospital Old Harbour Health Centre Portmore Health Centre	St. James Type 5 Cornwall Regional Hospital Savanna-La-Mar Health Centre	May Pen Hospital Black River Hospital Mandeville Hospital
Totals	5	4	3	3

### **D. Objectives of the PMTCT Programme**

The primary goal of the pilot was to stimulate the interest of all pregnant women, especially those in high-risk areas and those involved in high-risk activities, to be tested for HIV. Associated with the testing event was a significant counselling intervention aimed at reducing risky behaviour, appropriate family planning, and the acceptance of PMTCT practices. Counselling also emphasised the importance of disclosure by the mother to relevant healthcare providers.

The PMTCT pilot programme provided evidence-based guidelines to inform healthcare providers on how to provide care and prevent HIV transmission. The pilot's objective was to test a strategy to reduce transmission while:

- Providing on-going training for healthcare workers in preventing MTCT,
- Integrating VCT in antenatal clinics, and
- Treating HIV-infected women and their newborns with ARVs.

Under the PMTCT pilot, each participating health centre provided a comprehensive package of antenatal and postnatal care services, including VCT, ARVs to HIV-positive women and their infants, information on infant feeding options, and a supply of breast milk substitutes.

Under the pilot, 8,000 pregnant mothers were tested at 16 health centres in four parishes (Box 1). Programme components and activities were implemented as part of routine activities at primary healthcare antenatal and postnatal clinics. Hospitals attended all deliveries of HIV-positive mothers with modified clinical practices. The pilot covered the two major urban cities of Kingston and Montego Bay as well as health centres in rapidly growing parishes: St. Catherine (urban/rural) and St. Mary (rural).

**Box 1: Participating Health Centres by Parish**

**KSA Parish**

1. Maxfield Park Health Centre
2. Comprehensive Health Centre
3. Duhaney Park Health Centre
4. Harbour View Health Centre
5. Olympic Gardens Health Centre

**St. Catherine Parish**

1. St. Jago Park Health Centre
2. Greater Portmore Health Centre
3. Old Harbour Health Centre
4. Linstead Health Centre

**St. James Parish**

1. Montego Bay Type 5 Health Centre
2. Catherine Hall Health Centre
3. Cambridge Health Centre
4. Maroon Town Health Centre

**St. Mary Parish**

1. Annotto Bay Health Centre
2. Gayle Health Centre
3. High Gate Health Centre

### III. RAPID ASSESSMENT

QAP conducted a retrospective assessment during September 2002–May 2003 at all 16 health centres.

#### A. Rationale and Objectives

The overall purpose of the assessment was to inform future programming in order to build on the pilot's successes and remedy its failures. Understanding the effectiveness of the PMTCT programme is crucial for scale-up. The success of a PMTCT programme in reducing sero-conversion among newborn infants is determined by many factors, including the administration of ARVs (nevirapine or zidovudine [AZT]) to both HIV-positive mothers and their newborns; infant feeding practices; access to and use of well-baby care; and the health system's ability to provide care, including counselling and support to both the HIV-positive mother and her newborn. Prior to the assessment, very little was known about the efficacy of the pilot in reducing sero-conversion among infants. Specific assessment objectives were to determine:

- Sero-conversion rates among infants of HIV-positive mothers who did or did not receive ARVs,
- Mortality/morbidity rates among children of HIV-positive mothers,
- The infant feeding practices of HIV-positive mothers and the impact of such practices on sero-conversion,
- The methods used for early detection of neonatal HIV infection,
- The therapy used for disease suppression in HIV-positive children,
- The morbidity/mortality rates in children with the current treatment,
- The attitudes of women towards PMTCT,



- The psychosocial issues that influence the use of healthcare facilities by HIV-infected individuals, and
- Which health services are available to HIV-positive mothers and their infants in the pilot project areas.

## **B. Methodology**

The study was conducted in three phases. The first phase consisted of developing data collection tools. The second involved the collection of blood samples and quantitative and qualitative data from HIV-positive mothers, service providers, and programme managers. The third phase consists of compiling this report, coordinating its dissemination, and assisting the MOH in developing a strategy for improving efficacy of the PMTCT programme, as warranted.

**Record review:** QAP reviewed the dockets and ward delivery books for all confirmed HIV-positive pregnant women for the period January 2001 through December 2002 to identify services received since the birth. Aggregate HIV test results for all the women participating in the pilot programme were also extracted from the National Public Health Laboratory. Stillbirths were excluded.

**Survey and interviews of mothers:** Trained contact investigators attempted to find all the women and infants who were identified via docket review. The women who were located and who gave written informed consent were asked to respond to a questionnaire (see appendix). Core questionnaire concepts included demographics, economics, knowledge of HIV/AIDS transmission, perceived HIV-related stigma, perceived quality of care received from providers, social support, and the presence of AIDS-related disease at delivery. Additionally, the element of choice among women who consciously decided against receiving ARVs and did not reveal their status to the appropriate labour and delivery staff was qualitatively explored. Trained personnel conducted in-depth interviews of HIV-positive mothers on infant feeding, health-seeking behaviour, and other variables. Infants whose mothers consented were tested for HIV using the Determine<sup>®</sup> rapid or Berhing ELISA (Enzyme Linked Immuno Sorbent Assay) test. All positive cases were confirmed using the protocol at the National Public Health Laboratory.

**Patient medical record reviews:** Record reviews were conducted for all HIV-positive mothers and their most recent infant to identify services received since the birth.

**Facility observations and interviews:** A limited number of facilities were visited to identify clinical and non-clinical areas that need improvement within the process of preventing MTCT. During clinic visits, trained personnel held discussions with the clinic managers about the management information systems used to track efficiency and effectiveness at the clinic or programme level. They also interviewed providers to assess knowledge and skills regarding the PMTCT programme and services. Interviews of clients assessed client knowledge, practices, and satisfaction.

## **C. Study Administration**

QAP conducted a literature review to assess results of similar studies; of particular focus were methodologies used for such analysis. It also identified tools that had been developed previously for similar analyses. These tools were modified to meet the needs of the study.

The study team comprised a primary researcher, contact investigators (one for each region), and a data entry person. Data were collected, coded, and entered into EPI info software, and then analyzed using the SPSS 9.0 software programme. QAP provided technical assistance through its local and U.S.-based staff.

## **D. Limitations of the Study**

The difficulty in retrieving important and relevant information because of poor data recording practices in some health clinics was a major study limitation. In addition, 67% of the women who participated in the PMTCT programme, many residing in St. James Parish, could not be located. Some had relocated or died; a small percentage were reluctant to give relevant information, and another small percentage opted to discontinue the PMTCT programme after delivery and sought medical care from private physicians or

clinics outside the pilot areas. Some mothers were reluctant to have their infants tested and hence did not participate in the programme. These factors significantly weakened the study results and the extent to which inferences could be made.

#### **IV. RAPID ASSESSMENT RESULTS**

Each participating health centre was equipped to provide a comprehensive package of antenatal and postnatal care services, including VCT, provision of ARVs to HIV-positive women and their infants, information on infant feeding options, and a supply of breast milk substitutes. The rapid assessment revealed shortcomings in five areas: testing, documentation, mothers' failure to notify hospital staff of their HIV-positive status, monitoring and follow-up, and training. Each is detailed below.

##### **A. Testing**

Four areas relating to testing were identified as problematic.

**Pre-test counselling:** Of the sub-population reviewed, 72% indicated that they received information about the HIV test. This counselling was usually provided through group sessions. The information presented lacked basic prevention information, such as modes of transmission, risk reduction, and vulnerability associated with high-risk behaviour.

**Post-test counselling:** Only 58% of individuals interviewed indicated that they were counselled on the meaning of the test result. A public health nurse delivered results to 37% of the patients, and a contact investigator did so for 32% of patients.

**Laboratory support:** Both the number of and training for laboratory technical assistants were inadequate. Training specifically related to HIV testing had not been provided. Of particular concern was the lack of documented, standard procedures for handling blood samples. Also, personnel were uncertain of the retrieval of results. Lastly, the National Public Health Laboratory lacked capability, so the turn-around time for test results was four to six weeks in most cases.

**Supplies:** Basic supplies, such as sharps containers and materials for post-exposure prophylaxis, were lacking.

##### **B. Documentation**

Documentation on the HIV status of pregnant women was poor at the primary care level. In addition, documentation of counselling events, health education discussions, and similar PMTCT efforts were lacking.

##### **C. Mothers' Failure to Notify Hospital Staff of Their HIV-Positive Status**

Approximately 67% of HIV-positive mothers did not divulge their HIV status at the hospital. This high percentage would of course reduce rates of antiviral administration for both mothers and babies (reported below).

##### **D. Monitoring and Follow-up**

Though mothers felt that they had easy access to care for ill infants, only 67% were told upon discharge where to go for follow-up care.

Post-delivery follow-up of mothers and infants was unsatisfactory, and only limited specific interventions other than ARVs were available to mothers and their families.

Follow-up of infants and the provision of nutritional supplements and formula were also limited.

##### **E. Training**

Several gaps were identified in the training of healthcare workers. Some nurses and doctors lacked adequate training in counselling, and the first person to receive HIV results at the parish level varied. There were no clear guidelines on the referral of HIV-positive mothers, and no clear guidelines/

supervision of healthcare workers providing PMTCT counselling. Modification of delivery procedures for HIV-positive women were also not clearly understood and accepted by hospital staff.

## **V. PROGRAMME RESULTS**

### ***A. Prevalence of HIV among Pregnant Women: 2001 and 2002***

From the 16 selected health centres in the four parishes, the study identified 8,116 pregnant women who had been tested for HIV between January 2001 and December 2002, representing 12% of women delivering in the public sector. In 2001, 62 (1.4%) tested positive, and in 2002, 61 (1.6%). Note that the prevalence of HIV was higher in 2002 despite the decrease in the number of women tested. We identified 176 HIV-positive cases, including 123 women who tested positive during the study period and 53 who had tested positive before their pregnancy that was ongoing during the study period. Of the 176 cases, the largest proportion (57%) lived in KSA and the smallest (8%) in St. Mary. St. Catherine registered 19% of the HIV-positive cases and St. James, 15%.

### ***B. Use of Antiretroviral Therapy for Pregnant Mothers***

Of the 176 HIV-positive cases, there were data on 81% (143) regarding the administration of ARV therapy to mothers prior to the delivery. Of those on whom data were found, 77% [110] received ARVs: 102 received nevirapine, and eight received AZT. Thirty-three (23%) of the cases with data on the administration of ARV therapy did not receive it. The highest percentage of reported cases not receiving ARV therapy was found in St. Catherine at 50%.

### ***C. Use of Antiretroviral Therapy for Infants***

Of the 176 infants, 77% (136) of records had data on the administration of ARV therapy. Of these 136, 83% (113) received ARV prophylaxis, including 77% (105) who received nevirapine and 6% (8) who received AZT. Twenty-three (17%) of the infants did not receive therapy.

### ***D. Profile of Women Who Participated in the PMTCT Programme***

- Sixty-five questionnaires were completed: 26 (40%) from St. Catherine, 25 (38%) from KSA, and 7 (11%) each from St. Mary and St. James.
- Fifty-three (82%) of the women were single, 3% were married, and the rest were in common law unions.
- Ten women were 19 or younger; the mean age was  $26.6 \pm 6.2$ , ranging from 18 to 42.
- Only 23 (35%) had attained a high school education; 54 (83%) were employed or self-employed.
- Some 45% had three or more children, and 10% had five or more.
- Five (8%) of the women reported being pregnant when they completed the questionnaire: Only three of these five HIV-positive, pregnant women were on antiretrovirals at the time of the interview.

#### **1. Beliefs on HIV transmission**

- Of women interviewed 59 (91%) believed that HIV could be transmitted from an infected mother to her baby.
- Almost all (95%) indicated that HIV could be transmitted through breast-feeding.
- Almost all (95%) indicated that antiretrovirals could prevent MTCT.
- A few (16%) indicated that breast-feeding could prevent MTCT.
- Over a third (38%) indicated that the law should allow HIV-positive women to have an abortion.

#### **2. VCT and partner notification**

- Almost all women (97%) thought that all pregnant women should take an HIV test.
- Only 38 (58%) reported receiving counselling prior to taking an HIV test: 72% of these had individual counselling and 28% had group sessions.
- Only two women reported not receiving post-test counselling.
- A small majority (58%) were interested in knowing their HIV result on the same day.

- Thirty-six (62%) of the 58 women who responded to questions regarding partners reported that their current partner did not know his HIV status, although 59% of them reported that their partner had been contacted and asked to take an HIV test.

#### **E. Multidisciplinary Approach**

- Thirty-seven (57%) women were referred to the high-risk clinic and 58% to the nutritionist.
- Some 90% reported receiving advice on healthy nutrition and meal planning and to avoid breast-feeding their infant.

#### **F. PMTCT Interventions**

- Thirty-six (58%) women took antiretrovirals (97% nevirapine, 3% AZT) before delivery, with 77% taking the medication at the onset of labour.
- Forty-five (69%) received replacement feeding, but 17% complained that it was difficult to receive the formula feeds, and 34% received feeds for less than the standard six months.
- About 55% reported feeling uncomfortable with being unable to breast-feed their child; 25% reported breast-feeding at some point.

#### **G. Infants**

- Data were available on 63 children, with a mean age of  $22.6 \pm 5.4$  months, ranging from 9–33 months.
- The largest percentage (44%) were born at the Victoria Jubilee Hospital in Kingston, 29% at the Spanish Town Hospital, 11% at Cornwall Regional Hospital, and 8% at Annotto Bay Hospital.
- All infants were born in their mother's stated parish of residence.
- Seven babies (11%) were premature, and 13 (21%) had a nursery admission prior to discharge.
- Forty-two of 59 (71%) reportedly received medication for PMTCT, uniformly nevirapine.
- Fourteen (22%) of these infants had had at least one hospitalisation since discharge.
- Of those admitted to the nursery prior to discharge, 25% had had at least one admission after discharge, compared to 23% of those who were not. This was not significantly different ( $p \leq 0.87$ ).
- Three fourths of mothers reported that they were not satisfied with the care their babies received during hospitalisations.
- Forty-three of 59 (73%) reported that their infants had had an HIV test prior to this study. Final results were available for 51, of which 16% were positive. Three positive infants were under 18 months, and five were over 18 months and thus true positives.
- Of infants whose mothers reported having taken ARVs, 10% were HIV-positive, and of those who reported not having taken ARVs, 23% were HIV-positive (Table 2; not statistically significant at  $p < 0.2$ ). However, the attributable risk of HIV transmission was –19 for those infants whose mothers received the medication, clearly indicating the protective value of nevirapine.

**Table 2. Cross-Tabulation of Infant HIV Results and ARV Prophylaxis**

Mother's ARV Prophylaxis	Infant's HIV Status		Total
	Positive	Negative	
Mother Took ARV before Delivery	3	26	29
Mother Took No ARV	5	16	21
Total	8	42	50

$p \leq 0.2$ .

### H. Factors Affecting Transmission

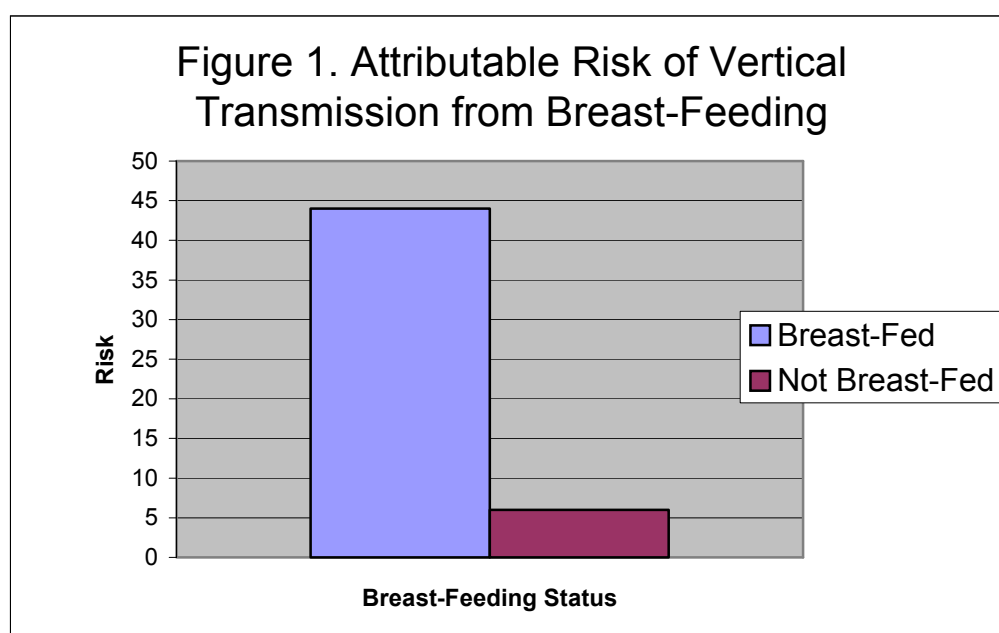
Of infants whose mothers breast-fed at some point, 50% were HIV-positive; of infants who were not breast-fed, 6% were HIV-positive (Table 3;  $p \leq 0.001$ ).

**Table 3. Cross-Tabulation of Infant HIV Results and Breast-Feeding**

Breast-Feeding Practice	Infant's HIV Status		Total
	Positive	Negative	
Breast-fed	6	6	12
Not breast-fed	2	34	36
Total	8	40	48

$p \leq 0.001$

The attributable risk of vertical transmission of HIV to infants who were breast-fed at some time was 44% (Figure 1).



- Of 29 mothers who reportedly received nevirapine, 11% breast-fed their infants at some point, and 89% did not.
- Of those who breast-fed and received ARVs, 69% of their infants had a final HIV-positive result, compared to 4.2% of those who did not breast-feed and received nevirapine.

Though these numbers are small, the differences were statistically significant ( $p \leq 0.001$ ).

### I. High-Risk Clinic

Being referred to a high-risk clinic and participation in the PMTCT programme were also found to be protective, with a relative risk of  $-14$  and  $-10$ , respectively; however, these differences were not statistically significant ( $p < 0.2$ ).

### J. Other Factors Associated with Transmission

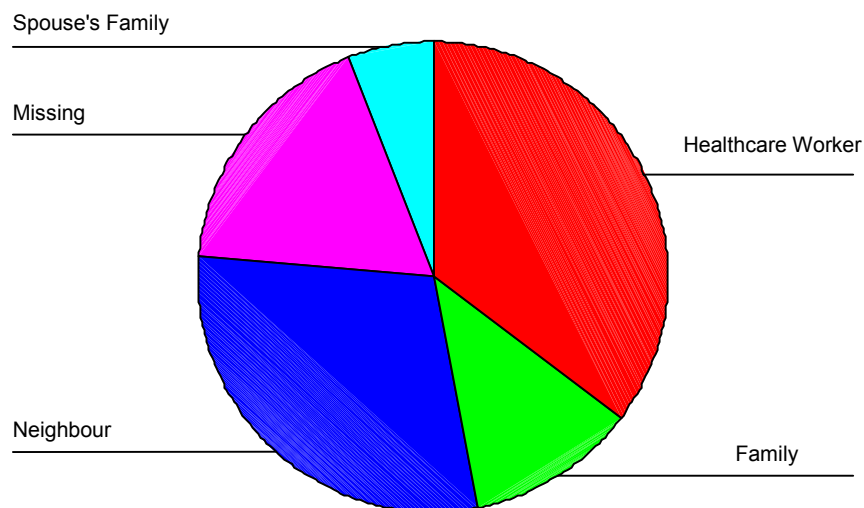
Of infants who reported having hospital admissions, 57% were found to be HIV-positive, with relative risk of  $48$  ( $p < 0.02$ ).

Participation in a social group had relative risk of  $34$  ( $p < 0.06$ ), suggesting a possible increased transmission rate among those who participated in such group.

### K. Stigma, Confidentiality, and Victimization

- Of mothers interviewed, 95% reported treatment at the health centre as good or better; 86% reported good or better treatment at the hospital.
- Nearly 30% of the participants reported feeling victimized because of their HIV status; most of this percentage reported being victimized by healthcare workers (35%) or neighbours (29%). See Figure 2.

Figure 2. Sources of Victimization



## VI. CONCLUSION

Though the efficacy of nevirapine in the PMTCT is proven, the rate of mixed feeding among those who received it and hence the rate of vertical transmission of HIV are still unacceptably high.

Stigma and discrimination remain a serious barrier for people living with HIV/AIDS to services within the healthcare sector. The possibility of victimization by healthcare workers may contribute to women's not disclosing their HIV-positive status to hospital staff at the time of delivery.

## VII. RECOMMENDATIONS

- The research reported here should be followed up with more focused research that would be based on the findings here and would improve the Health Ministry's ability to serve HIV-infected and -affected individuals.
- Collaboration between the public clinics and private physicians also needs to be strengthened.
- Additional training of health personnel should ensure effective post-test counselling of HIV-positive, pregnant women, empower the mothers, and mitigate stigma. The continued follow-up of women and infants in the programme must be improved with enhanced mechanisms to empower more HIV-positive women to select and carry out infant feeding options that minimise the risk of MTCT.
- Despite the efforts of the Ministry of Health in educating the population about HIV/AIDS, there is still marked stigma associated with the disease. We learned that several persons had moved from their communities due to fear. Further education with emphasis on combating stigma is required.



## APPENDIX: PMTCT PARTICIPANT PROGRAMME FOLLOW-UP QUESTIONNAIRE

Knowledge, attitudes and practices of women who have participated in the prevention of mother-to-child transmission (PMTCT) of HIV programme and the outcome of the HIV-exposed infants\*

Objective: To identify areas for improvement in healthcare delivery systems for the PMTCT programme. We need your help to assess the system and develop strategies to improve health services for women and children in the programme.

### Part I. Demographics

1. What is your date of birth? \_\_\_\_\_ Age? \_\_\_\_\_
2. How many children do you have? \_\_\_\_\_
3. What is your marital status? a. Single \_\_\_ b. Married \_\_\_ c. Divorced \_\_\_ d. Common law \_\_\_  
e. Widowed \_\_\_ f. Other: Specify \_\_\_\_\_
4. Which parish do you live in? \_\_\_\_\_
5. What is your occupation? \_\_\_\_\_
6. Are you presently employed? Yes \_\_\_ Self-employed \_\_\_ No \_\_\_
7. What was the highest level of education achieved?  
a. No formal education \_\_\_ f. HEART \_\_\_  
b. Primary \_\_\_ g. University \_\_\_  
c. Junior Secondary \_\_\_ h. Other tertiary \_\_\_  
d. Secondary/High \_\_\_ i. Others: Specify \_\_\_\_\_  
e. Technical \_\_\_

### Part II. Knowledge

Answer Yes, No, or Don't know to the following questions:

- |   | Yes | No  | Don't Know |
|---|-----|-----|------------|
| 8. Can HIV be transmitted from one person to another...                                       |     |     |            |
| a. By oral sex?   | ___ | ___ | ___        |
| b. By having sex without a condom?  | ___ | ___ | ___        |
| c. From an infected mother to her baby?   | ___ | ___ | ___        |
| d. Through mosquito bites?  | ___ | ___ | ___        |
| e. Through breast milk?   | ___ | ___ | ___        |
| f. By shaking hands with an infected person?  | ___ | ___ | ___        |
| g. Through saliva from an infected person?  | ___ | ___ | ___        |
| h. Through anal sexual intercourse?   | ___ | ___ | ___        |
| i. By using the same utensils used by an infected person?                                     | ___ | ___ | ___        |
| 9. How can a pregnant woman prevent her baby from becoming infected if she is HIV infected... | Yes | No  | Don't Know |
| a. By taking antiretroviral drugs?  | ___ | ___ | ___        |
| b. By giving the baby breast milk?  | ___ | ___ | ___        |
| c. By not breast-feeding?   | ___ | ___ | ___        |
| d. By kissing and hugging the baby?   | ___ | ___ | ___        |
| e. By making sure the baby receives ARVs before discharge from the hospital?                  | ___ | ___ | ___        |

\* Edited/reformatted for publication purposes.



Answer True or False to questions 10–11.

10. An HIV-positive woman who is pregnant does not need to use a condom when having sex with her partner.

True \_\_\_ False \_\_\_

11. I would use a condom at all times to prevent transmission.

True \_\_\_ False \_\_\_

12. Answer Yes or No to the following questions:

Who is at high risk for getting HIV/AIDS infection?

- a. Persons who have many sexual partners?

Yes \_\_\_ No \_\_\_

- b. Homosexual and bisexual men?

Yes \_\_\_ No \_\_\_

- c. Persons who consistently use condoms?

Yes \_\_\_ No \_\_\_

- d. Prostitutes?

Yes \_\_\_ No \_\_\_

- e. Intravenous drug users?

Yes \_\_\_ No \_\_\_

- f. Persons who have unprotected sex?

Yes \_\_\_ No \_\_\_

- g. Babies of HIV-positive mothers?

Yes \_\_\_ No \_\_\_

### Part III. Perception

To indicate your opinion on each of the following, put an X in the appropriate column:

13. What are your opinions about HIV transmission?

	Strongly Agree	Agree	Disagree	Strongly Disagree	Unsure
a. I think in Jamaica HIV is transmitted primarily by homosexuals/bisexuals					
b. ARVs can prevent a baby from contracting HIV from an HIV-positive mother					
c. I think anyone having unprotected sex can get HIV					
d. I don't believe condoms can prevent the contraction of HIV					
e. HIV can be transmitted through breast milk					
f. I believe in abstaining from sex to prevent spreading HIV					

### Part IV. General Information

Answer Yes or No to the following questions:

14. Does your current partner know his HIV status?

Yes \_\_\_ No \_\_\_

15. Was your partner contacted after your results came back positive?

Yes \_\_\_ No \_\_\_

16. Was your partner asked to take an HIV test?

Yes \_\_\_ No \_\_\_

17. Should the law allow pregnant women who know they are HIV-positive to have an abortion?

Yes \_\_\_ No \_\_\_

18. Do you believe that all pregnant women should routinely take an HIV test?

Yes \_\_\_ No \_\_\_

### Part V. PMTCT Programme Follow-up

19. Did you participate in the P-MTCT programme?

Yes \_\_\_ No \_\_\_

20. Which clinic did you attend? \_\_\_\_\_

21. Were you given pre-test counselling before you were tested for HIV?

Yes \_\_\_ No \_\_\_

22. How was the pre-test counselling conducted?

Group \_\_\_ Individual \_\_\_

23. Did you receive post-test counselling?

Yes \_\_\_ No \_\_\_

24. Who gave you your test result (staff category)? \_\_\_\_\_

25. How long after taking the test did it take for you to receive your result? \_\_\_\_\_

26. Would you have preferred to receive your result on the same day?

Yes \_\_\_ No \_\_\_

27. If the answer is yes, how long after? \_\_\_\_\_

28. Were you referred to the (a) high-risk clinic? Yes \_\_\_ No \_\_\_  
 (b) nutritionist/nutrition assistant? Yes \_\_\_ No \_\_\_
29. Were you advised (a) on healthy nutrition and meals? Yes \_\_\_ No \_\_\_  
 (b) to avoid smoking and alcoholic beverages? Yes \_\_\_ No \_\_\_  
 (c) not to breast-feed Yes \_\_\_ No \_\_\_
30. Did you take medication for PMTCT? Yes \_\_\_ No \_\_\_
31. If yes,  
 a. What did you take? Nevirapine \_\_\_ ZDV \_\_\_  
 b. If you took nevirapine, was it at the onset of labour? Yes \_\_\_ No \_\_\_ Not Applicable \_\_\_  
 c. If you took ZDV, did you start at 7 months? Yes \_\_\_ No \_\_\_ Not Applicable \_\_\_
32. If you delivered at a hospital, what was the length of your hospital stay? \_\_\_\_\_
33. Did you receive replacement feeding for your infant? Yes \_\_\_ No \_\_\_  
 Where did you receive your replacement feeding? \_\_\_\_\_
35. How easy was it to receive the replacement feed? Very Easy \_\_\_ Easy \_\_\_ Difficult \_\_\_
36. How long did you receive replacement feed? 2 mos. \_\_\_ 4 mos. \_\_\_ 6 mos. \_\_\_ > 6 mos. \_\_\_
37. Did you feel comfortable not breast-feeding? Yes \_\_\_ No \_\_\_
38. Did you breast-feed your infant at anytime? Yes \_\_\_ No \_\_\_
39. If the answer to question 38 is yes,  
 a. How often did you breast-feed? \_\_\_\_\_  
 b. Did you give replacement feed along with breast milk? Yes \_\_\_ No \_\_\_
40. Were you told to take your infant to the hospital at 6 weeks for HIV testing? Yes \_\_\_ No \_\_\_
41. (a) Did you take your infant for HIV testing? Yes \_\_\_ No \_\_\_  
 (b) If yes, have you received any information about the HIV test? Yes \_\_\_ No \_\_\_
42. How old was your infant when you introduced other foods? \_\_\_\_\_
43. Have you received additional counselling since you delivered? Yes \_\_\_ No \_\_\_
44. If yes, from whom? \_\_\_\_\_
45. Do you participate in any social support group? Yes \_\_\_ (Name \_\_\_\_\_) No \_\_\_
46. If yes, what kind of support are you receiving? \_\_\_\_\_
47. Are you satisfied with the support you are receiving? Yes \_\_\_ No \_\_\_
48. What are you doing to  
 a. Remain healthy? \_\_\_\_\_  
 b. Prevent contracting opportunistic infections? \_\_\_\_\_
49. Are you currently pregnant? Yes \_\_\_ No \_\_\_
50. If not, what method of contraception are you using to prevent pregnancy? \_\_\_\_\_
51. What is your current health status? Excellent \_\_\_ Good \_\_\_ Fair \_\_\_ Poor \_\_\_
52. Are you currently on ARVs? Yes \_\_\_ No \_\_\_
53. If yes, which \_\_\_\_\_
54. If you were sick, where would you go for treatment and care? \_\_\_\_\_

## Part VI. Infant Profile

55. What was the age of your child at his/her last birthday? \_\_\_\_\_
56. What is your child's date of birth? \_\_\_\_\_
57. Where was your infant delivered? \_\_\_\_\_
58. What was the baby's weight at birth? \_\_\_\_\_
59. What was his/her gestational age? Premature \_\_\_ Term \_\_\_
60. Did your baby receive medication at birth for PMTCT? Yes \_\_\_ No \_\_\_
61. If yes, which? Nevirapine \_\_\_ ZDV \_\_\_
62. If you delivered at a hospital, was your baby admitted to the nursery during your hospital stay? Yes \_\_\_ No \_\_\_
63. Has he/she been admitted to hospital since birth? Yes \_\_\_ No \_\_\_

64. If yes,  
 a. Which hospital? \_\_\_\_\_  
 b. Number of admissions? \_\_\_\_\_  
 c. What were the major health problems? \_\_\_\_\_  
 d. Were you satisfied with the care your baby received? Yes \_\_\_ No \_\_\_

65. Has your infant been tested for HIV? Yes \_\_\_ No \_\_\_

66. If yes,

Age at Test	Type of Test	Results

67. Has your infant received any immunizations? Yes \_\_\_ No \_\_\_

68. If not, why not? \_\_\_\_\_

69. If yes,  
 (a) BCG \_\_\_\_\_ date received \_\_\_\_\_  
 (b) DPT \_\_\_\_\_ date received \_\_\_\_\_  
 (c) OPV \_\_\_\_\_ date received \_\_\_\_\_  
 (d) MMR \_\_\_\_\_ date received \_\_\_\_\_  
 (e) Others (specify and include date received) \_\_\_\_\_

70. What is the current status of your baby?

- a. Alive and well \_\_\_  
 b. Alive and ill \_\_\_  
 c. Dead \_\_\_ Cause of death \_\_\_\_\_ Date of death \_\_\_\_\_

71. If your child is alive and ill, what is the child's diagnosis? \_\_\_\_\_

72. Is your child on ARVs? Yes \_\_\_ No \_\_\_

73. If yes, which \_\_\_\_\_

74. Any comments you would like to make about the PMTCT programme? \_\_\_\_\_

## Part VII. Stigma

75. How were you treated at the health centre? Exceptional \_\_\_ Good \_\_\_ Fair \_\_\_ Poor \_\_\_

76. How were you treated at the hospital? Exceptional \_\_\_ Good \_\_\_ Fair \_\_\_ Poor \_\_\_

77. Have you felt victimized because of your HIV status? Yes \_\_\_ No \_\_\_

78. If no, \_\_\_ not applicable. If yes \_\_\_

a. How? \_\_\_\_\_

b. By whom

i. Health worker Yes \_\_\_ No \_\_\_

ii. Family member Yes \_\_\_ No \_\_\_

iii. Neighbour Yes \_\_\_ No \_\_\_

iv. Other: Specify \_\_\_\_\_

c. How has this affected you? \_\_\_\_\_

d. How have you dealt with the situation? \_\_\_\_\_

79. Do you think your HIV status was kept confidential at the health facilities you attended? Yes \_\_\_ No \_\_\_

**THANK YOU FOR YOUR COOPERATION**

Signature of Participant: \_\_\_\_\_

Date Interviewed: \_\_\_\_\_



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